

# CME Article

## HIV Disease Surveillance

### Collaboration between Medicine and Public Health

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Public Health Surveillance is critical to the management of programs designed to control the epidemic of HIV-AIDS. Surveillance defines changing trends, helps to formulate preventive initiatives and evaluate their effectiveness, and to allocate resources. Collaboration between clinical medicine and public health is essential to achieve reliable surveillance.

#### LEARNING OBJECTIVES

- I. To describe three changing trends in HIV disease in New Jersey.
- II. To recognize the need for collaboration between medicine and public health to better understand and respond to the HIV epidemic in New Jersey.
- III. To recognize the importance of HIV-AIDS surveillance.

In the busy daily practice of medicine, submitting required disease reports to the health department is rarely given a high priority. These reports constitute the basis of public health surveillance, which is important for many diseases, including HIV-AIDS. The HIV and AIDS cases reported to the New Jersey Department of Health and Senior Services (NJDHSS) provide the foundation for decisions relating to resource allocation, including funding for counseling and testing, medical care,

and access to the AIDS Drug Distribution Program formulary; planning and evaluation of prevention services; evaluation of the implementation of the U.S. Public Health Service (PHS) for the prevention of perinatal HIV transmission and for the prevention of opportunistic infections; presence and transmission of variant strains of HIV and changing trends in the epidemic.

Public health surveillance is an important tool that classifies data, interprets data, and, most importantly, helps guide interventions in public health problems. Surveillance also has a role in evaluation during which new information is collected and analyzed to quantify the success of the intervention in the public health problem. AIDS has been a reportable disease by regulation in New Jersey since 1986. New Jersey was the first high-prevalence state to implement name-based HIV reporting in October 1991. Through December 31, 2001, a total of 43,009 AIDS cases were reported and 16,412 persons with HIV disease (not AIDS) were reported.<sup>1</sup>

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New Jersey has the fifth highest prevalence of AIDS cases in the United States, ranks third in pediatric AIDS cases, and has the highest proportion of women among the cumulative AIDS cases in the country.<sup>2</sup>

Surveillance data is used to determine federal funding levels for cities and states under the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990. The Health Resources and Services Administration distributes CARE Act dollars to states and cities for the development of comprehensive care systems for low-income individuals and families lacking other sources of payment for these services. The formula portion of the CARE Act awards is based on a 10-year weighted average of AIDS cases reported to the Centers for Disease Control and Prevention (CDC), which serves as an estimate of the number of individuals living with HIV and AIDS in each state and local jurisdiction.

During federal fiscal year 2002, approximately \$82 million from the Ryan White program was allocated to New Jersey under different titles of the CARE Act. Comprehensive surveillance activities play an important role in ensuring that New Jersey residents receive their fair share of federal resources to address this burgeoning epidemic.

In addition to federal funding, HIV–AIDS surveillance data is also used in the annual appropriations process by the NJDHSS and the legislature. Therefore, reporting all cases of HIV and AIDS to NJDHSS is imperative for sufficient federal and state funding.

Surveillance data are also used as part of the decision-making process for determining the number and distribution of counseling and testing sites that are needed. These counseling and testing sites provide free HIV counseling and assessment of serostatus and are also established, at least in part, on the number of reported HIV and AIDS cases. Physicians can refer patients to these sites; however, the results can only be sent to the physician with written permission from the patient. As with all HIV-infected persons, confidentiality must be strictly maintained according to NJAC 26:5C. Information on publicly funded counseling and testing sites can

be obtained from the NJDHSS by calling 609-984-6125 or on the NJDHSS web site at URL: [www.state.nj.us/health](http://www.state.nj.us/health).

## EVALUATION

Surveillance activities based on reported HIV–AIDS cases include evaluation of both the implementation and effectiveness of PHS recommendations. From the clinician's perspective of treating individual patients as well as the population-based health perspective of the NJDHSS, it is important to verify the effectiveness of PHS recommendations. New Jersey was one of the original venues in which a critically important set of recommendations of the PHS was validated: prevention of perinatal HIV transmission. The Pediatric AIDS Clinical Trials Group Protocol 076 (PACTG 076) proved that zidovudine (AZT, ZDV) use during pregnancy, labor, and delivery, and in the neonatal period can reduce perinatal HIV transmission from 25% to 8%.<sup>3</sup> In August 1994, the PHS published recommendations for the use of AZT to prevent perinatal HIV transmission. For children born in New Jersey in 1993, 33 (9%) of the HIV-exposed children received perinatal AZT. As a result of the PHS guidelines, this proportion increased markedly to 199 (76%) in birth year 2000. During these years, perinatal HIV transmission decreased from 73 (21%) in 1993, to 12 (4%) in 2000. Although there is continued room for improvement, statewide surveillance activities show that the PHS recommendations have been widely implemented and are indeed preventing perinatal transmission. Similar surveillance activities are currently being conducted in New Jersey to evaluate the implementation and effectiveness of PHS recommendations to prevent active tuberculosis in co-infected persons and to prevent *Mycobacterium avium* complex in HIV-infected children.

HIV reporting allows the NJDHSS to detect emerging trends in the epidemic a decade or more sooner than with AIDS-only surveillance. Recognition of these changes is important for daily interactions with patients, prevention planning, and resource allocation. A recently emerging trend is

an increasing number of persons living with HIV–AIDS, especially adolescents and women.

The number of adolescents living with HIV–AIDS increased over 50% from 146 in 1995, to 226 in 2001. This increase may be related to improved pediatric antiretroviral therapy and fewer opportunistic infections. The increasing number of adolescents with HIV disease has implications for prevention. First, vertical HIV transmission may occur from these adolescents to their children. Second, a larger prevalence of HIV-infected adolescents who may engage in high-risk behavior with other adolescents may result in a higher incidence of HIV among adolescents. NJDHSS is collaborating with the CDC on a study to describe, for the first time, the medical and social histories and pregnancy outcomes of a group of perinatally HIV-infected adolescent girls who were recently pregnant, and to assess, through a case-control study, the risk factors associated with pregnancy among these perinatally HIV-infected adolescents. The study is also designed to determine the prevalence of pregnancy among perinatally HIV-infected adolescents and to describe the viral characteristics of HIV subspecies transmitted across three generations.

An increase has been detected among women (those aged 12 and over) living with HIV–AIDS. The number of women living with HIV–AIDS increased by 37% from 7,534 in 1995, to 10,316 in 2001. New Jersey had the highest estimated proportion of women living with AIDS by the end of 1999. Women currently account for 28% of AIDS diagnoses; 38% of HIV diagnoses, and 36% of persons living with HIV–AIDS. This changing trend emphasizes the need for physicians to discuss HIV disease with women, perform a complete sexual and drug-use history, and offer (or provide a referral for) counseling and testing. Since the majority of the women are of reproductive age, it also emphasizes the need to comply with NJAC 8:61-3.1, which requires providers to give HIV counseling and offer HIV testing to pregnant patients. Recommendations for the prevention of perinatal HIV transmission should be followed for HIV-infected pregnant women.

The number of persons living with HIV–AIDS in

New Jersey has increased from 22,391 on December 31, 1995, to 30,535 on December 31, 2001. This increased prevalence of HIV–AIDS in the era of combination therapy may be due, in part, to a decrease in opportunistic infection–related mortality and/or an increasing incidence of HIV disease.

### NEW INITIATIVES

Patients on combination therapy who live longer with HIV disease will need medical care for such complications as hyperglycemia and diabetes mellitus, lipid abnormalities, fat redistribution, and lactic acidosis with hepatomegaly and hepatic steatosis.<sup>5,6</sup> The emerging history of HIV-infected persons on combination therapy has yet to be fully described. A new surveillance effort entitled “Survey of HIV Disease and Care (SHDC)” is being developed in collaboration with the CDC to determine access to and utilization of care, to better describe the clinical course of HIV-infected persons on combination therapy, to determine the occurrence of opportunistic infections, and to evaluate the implementation of PHS recommendations.

The increasing number of persons living with HIV–AIDS may lead to changing trends in new infections. Incident cases of HIV can be identified by collaboration between medicine and public health.

NJDHSS is starting a new CDC-funded project. This project depends on prompt notification (reporting) of patients newly diagnosed with HIV disease. The goal is to determine population-based HIV incidence through a new laboratory assay. Incidence data is particularly important for planning, targeting, and evaluating prevention interventions; planning and resource allocation for direct patient care; location and staffing of counseling and testing sites; and determining changing trends in the epidemic.

### SPECIAL STUDIES

Special epidemiologic studies are conducted by the NJDHSS. Investigations of unusual cases are conducted, for example, in situations in which there is

discordance between clinical presentation and laboratory findings. Recent special epidemiologic studies have identified the presence of variant strains of HIV in New Jersey and a case of HIV-1 group M subtype B (the most common strain of HIV in New Jersey and in the United States) that was not detectable using currently FDA-approved HIV diagnostic tests.<sup>7</sup> Identification of variant strains of HIV can provide the foundation for further epidemiologic studies describing the predilection for transmission, immunologic response, and treatment response for these emerging pathogens within the HIV epidemic. These special studies can provide information, and possibly laboratory specimens, for the development of diagnostic tests and viral load monitoring tests that consistently and reliably detect these strains. Detecting and monitoring these strains are crucial for diagnosis, medical management, and protection of the blood supply.

### COLLABORATION

In addition to HIV disease surveillance, the NJDHSS can collaborate with physicians to follow-up on HIV-infected persons. The Notification Assistance Program (NAP) is a statewide service of the NJDHSS designed to provide follow-up services to health care providers for HIV-positive patients who do not return for test results, counseling, and medical referrals. NAP can also contact the sexual or needle-sharing partners of patients to provide confidential counseling and testing. NAP is a voluntary, confidential service through which no partners will become aware of the source of the referral or the identity of the HIV-positive individual naming them. Health care providers interested in using NAP services for locating contacts or providing follow-up for their HIV-positive patients can call NAP at 877-356-8312.

Collaboration between medicine and public health is essential to control any major health problem in our community, and this cooperation has never been so important as in managing the AIDS epidemic. Clinicians provide a vital link to coun-

seling and testing services with which they can maximize the number of persons who know their serostatus, in addition to providing information on prevention and medical management for those who are infected. Case reports for HIV and AIDS allow public health personnel to optimize resource allocation, detect emerging trends, provide prevention services, and evaluate the effectiveness of PHS recommendations. The critical importance of federal and state funding commensurate with the size of New Jersey's HIV-AIDS population is an additional reason that surveillance must be conscientiously addressed by all members of the health care community. Providers and laboratories are required (NJAC 8:57-2.1-2.7) to report all cases of HIV, AIDS, CD4 counts of less than 200 or 14%, and viral load results to the NJDHSS. Information on reporting requirements and report forms can be obtained by calling 609-984-5940 or 973-648-7500. Surveillance data is available on the department's web site at URL: [www.state.nj.us/health](http://www.state.nj.us/health). *NJM*

### REFERENCES

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CME EXAMINATION: DEADLINE SEPTEMBER 30, 2004

“Hiv Disease Surveillance”

1. Which of the following is not described in the article as a changing trend in HIV-AIDS in New Jersey?
  - A. Increasing number of adolescents living with HIV-AIDS
  - B. Increasing number of children born infected with HIV-AIDS
  - C. Increasing number of persons living with HIV-AIDS
  - D. Increasing proportion of women reported with HIV-AIDS
2. HIV-AIDS surveillance data is used in New Jersey to:
  - A. Detect changing epidemiologic trends
  - B. Determine federal and state funding levels
  - C. Evaluate the implementation and effectiveness of PHS recommendations
  - D. All of the above
3. The Notification Assistance Program (NAP) is designed to:
  - A. Conduct special epidemiologic studies related to HIV-AIDS
  - B. Contact sexual or needle sharing partners of HIV positive patients
  - C. Notify the Centers for Disease Control and Prevention of unusual HIV-AIDS cases
  - D. Report HIV-AIDS case to the New Jersey Department of Health and Senior Services
4. Which of the following is reportable to the New Jersey Department of Health and Senior Services?
  - A. Cases of HIV or AIDS
  - B. CD4 counts less than 200 or 14%
  - C. Viral load results
  - D. All of the above
5. Which of the following best describes the prevalence of aids in New Jersey?
  - A. Highest overall prevalence in the United States
  - B. Highest prevalence of pediatric cases in the United States
  - C. Highest proportion of adolescents in the United States
  - D. Highest proportion of women in the United States

## ANSWER SHEET

## “Hiv Disease Surveillance”

Darken the correct answers

1. ☐ A ☐ B ☐ C ☐ D  
4. ☐ A ☐ B ☐ C ☐ D

2. ☐ A ☐ B ☐ C ☐ D  
5. ☐ A ☐ B ☐ C ☐ D

3. ☐ A ☐ B ☐ C ☐ D

Time spent reading this article and completing the learning assessment and evaluation: \_\_\_\_\_HOURS \_\_\_\_\_MINUTES

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*(This must be completed for this examination to be scored.)*

## “Hiv Disease Surveillance”

Check the appropriate answer below

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